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ABSTRACT

The newsletter offers perspectives on the provision of family support services for families with disabled members. An introductory article by Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, stresses the impressive coping skills exhibited by many such families and their relationship to service professionals. The newsletter's major article, by Dennis G. Olson, offers a conceptual framework to family support which includes five components: (1) crisis; (2) information/education; (3) skills development; (4) emotional support; and (5) task oriented activities. Examples of applying the process at the individual level, the community level, and the system or policy level are offered. Implications of the framework for family support and community systems are drawn. Also included in the newsletter is a statement by the Center on Human Policy offering principles to guide public policy toward families with developmentally disabled children. The newsletter also contains a brief description of in-home and out-of-home models of respite care, recommendations of a National Parents' Planning Meeting, and brief statements of opinion concerning such topics as parental dreams for their children, mobilization of community resources, parent groups, the parent/professional relationship, and parent involvement. (DB)

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SPRING 1988

FOCAL POINT

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FAMILY SUPPORT
Perspectives on the Provision of Family Support Services

Madeleine Will
Assistant Secretary for Special Education and Rehabilitative Services
U.S. Department of Education

American families have changed dramatically from the traditional families of a generation ago. Today's families consist of more single parents and two-wage earners than did families of the 1960's and early 1970's. Added economic burdens, increased stress, lack of leisure time, and less contact with the extended family due to geographic mobility also contribute to current changes in the American family unit.

Families whose members have disabilities are dealing with these changes and are coping with the same challenges that other families face. Indeed, all family members strive to carry out their responsibilities in the face of competing demands. The major difference is that families with disabled members have many additional stresses--they require special support services, must ensure that these services are available in their communities, must deal with a variety of service professionals on a regular basis, and they must make sure that the family member with special needs has the transportation and service plans necessary for receiving these services. In addition, families with special needs must balance their lives and give attention and support to the needs of *all* family members. It is not easy, but many families are succeeding.

Whether or not parents and service professionals can agree on the criteria for success, the fact remains that the majority of families prevail over the challenges that face them. Yet, in the field of disability, the assumption is often made that family members with special needs are burdens, and that family units experiencing the presence of disabilities are dysfunctional or

Madeleine Will

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even pathological. This notion must be totally rejected. Service professionals who deal on a daily basis with families that have members with disabilities, have been inspired by these families' ability to cope and to achieve happiness and well-being. Certainly all families, including those with children and youth who do not experience disabilities, have their share of problems, crises and concerns. Overwhelming evidence, however, confirms that members with disabilities can be successfully integrated into families, and that family life can indeed be happily sustained.

One of the primary reasons so many families have been successful has been a greater recognition of the role of family support services in increasing the well-being of families with special needs. Parent organizations have also played a pivotal role in the improvement and expansion of support efforts for families in crisis. This issue of *Focal Point* reflects the growing awareness among the professional service community of the importance of support to families with members who have disabilities. Much has been accomplished in a relatively short period of time; however, much remains to be done if all families with special needs are to receive the services necessary to ensure the integrity of the family unit, and the best possible quality of life.

Family members must be willing to work with service professionals in developing service plans to fit individual needs; at the same time, these professionals must be flexible, and be willing to "go the extra mile," in spite of limited resources, to provide family members with the tools necessary to live and work cohesively as a unit. This is not an easy task, but it is one which will yield tremendous results.

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We invite our audience to submit letters and comments.

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A Developmental Approach to Family Support: A Conceptual Framework

Dennis G. Olson

Families whose children have severe emotional disturbances have many similarities. They are not, however, a homogeneous group: at any particular point in time families do not all have the same needs or desires. In taking steps to provide family support, it is critical to understand the developmental process many families with seriously emotionally disturbed children encounter. Once the process is understood, efforts addressing family needs can become more focused. A framework is presented here for understanding the developmental process and its importance to efforts supporting parents.

THE FRAMEWORK

The framework consists of five components: (1) crisis; (2) information/education; (3) skills development; (4) emotional support; and (5) task-oriented activities. While presented and initially discussed separately, they are interrelated and one cannot be addressed without the other. The components are separated in the framework to facilitate articulation of the developmental process families experience and provide a framework for focusing on the specific needs of families in the larger context of their changing and comprehensive needs.

Crisis Phase. By the time a child's problems have reached a level of persistence and severity sufficient to warrant attention by the formal service delivery system, the problems have reached a point where the family can no longer effectively deal with them. The family is in crisis and needs help to stabilize the situation.

It is difficult for anyone in crisis to address much more than their immediate needs. It is not a time for assimilating new information, developing new skills, participating in insight-oriented therapy or taking an objective look at possible options. People in crisis need relief and crisis stabilization before anything else is done.

Relief for families may come in the form of a short break through a respite program, some support and practical solutions or through the intervention of an in-home crisis service. Simply stated, the crisis must be stabilized before the family can move forward to better meet their children's needs. Interventions focused on issues other than the family's immediate needs may not be helpful.

Information/Education. Once the immediate crisis is over, parents want to know, "Why is my child acting this way? What kind of help does he need? What services are available? How do the systems work? What are my legal rights? How do I get the help my child needs?"

Parents want straight factual information. Unfortunately, when in crisis they may not be able to fully understand or effectively use information. When the crisis is stabilized, information will more likely be assimilated. Information may be provided in a variety of ways: individual professional to parent, individual parent to parent, parent meetings with or without professionals, formal classes and seminars.

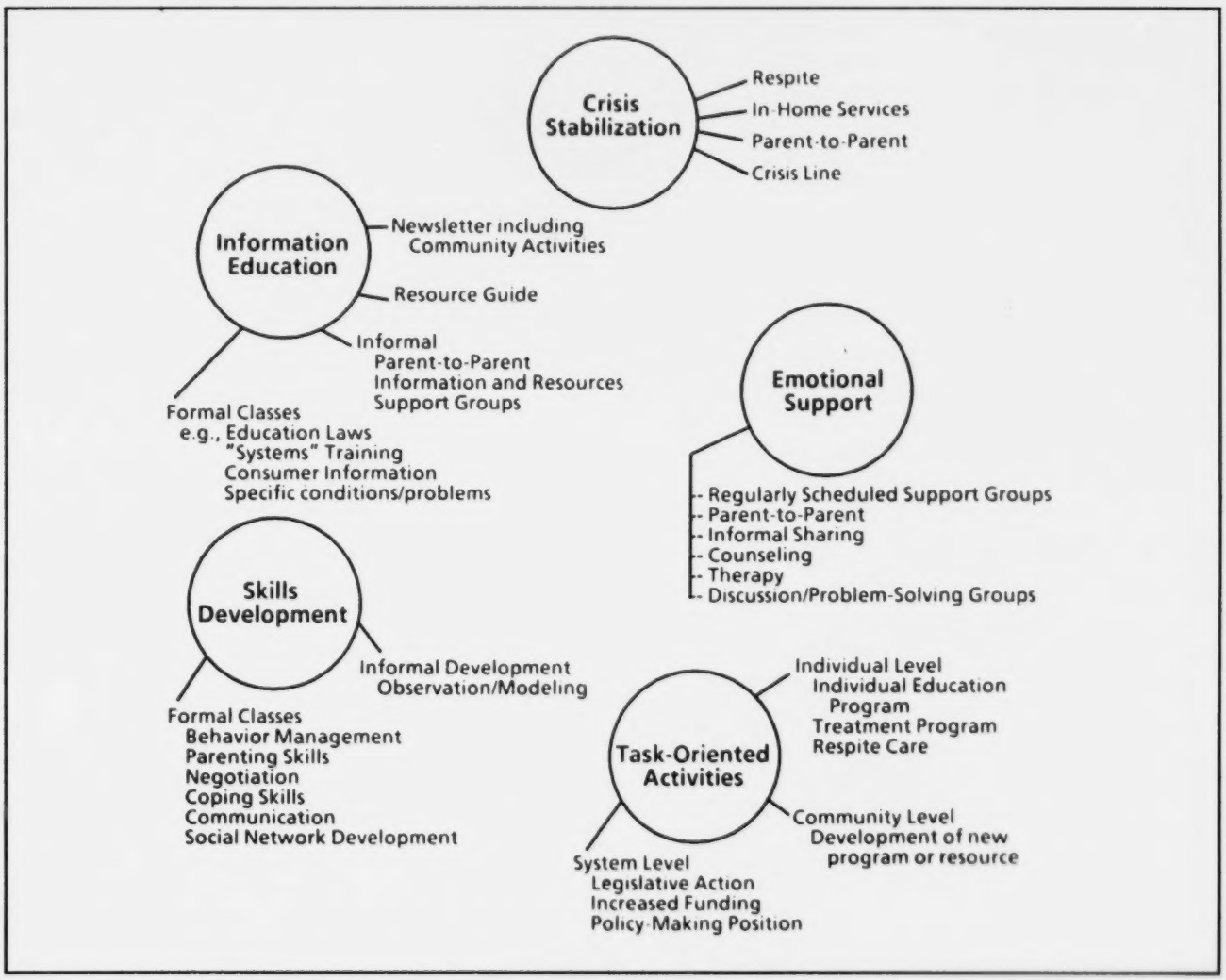
Skills Development. Once the crisis has been stabilized and specific information obtained, parents may want to develop skills to better address their child's needs. For example, some parents may want to develop better negotiation skills to more effectively deal with a reluctant school administrator. Others may want to improve their communication, coping, problem-solving, behavior management or other skills. Like consumers of any service, some parents may understand what skills they need to develop while others may require assistance in deciding which skills might prove beneficial to help them better meet the needs of their child. Skills, too, are not effectively developed when in crisis. Developing effective skills requires opportunities to practice the skill in a non-threatening environment where feedback is available.

Emotional Support. Emotional support is an essential element transcending all components of this framework. Different things are emotionally supportive to different people. One parent may only want a "warm line" or specific person to call when things get shaky. Another may want to be linked with a trained parent volunteer, while another may want to attend a for-

mal support group. Some parents may not believe they need support, or may find it difficult to request. They may find themselves comfortably "supported" through interactions with people while focusing on gaining new information or skills, performing tasks or engaging in activities.

Task-Oriented Activities. Once the crisis has been stabilized and the parent has obtained essential information, developed the necessary skills and feels supported, he or she may focus on task-oriented activities. These take place at a number of levels and may include the following:

- At the *individual* level, serving the child's or family's needs through developing an Individualized Education Plan (IEP), obtaining respite, or accessing a specific service;
- At the *community* level, working with other parents, the school and the parks department to develop a needed resource such as a collaborative day program during school vacation; and
- At the *system or policy* level, working to change legislative policy, increase funding for children with serious emotional handicaps, or serve on an agency's board.



Conceptual framework for a comprehensive and integrated family support system. Specific elements are not exhaustive. They are provided to illustrate elements that could be included.

It is important to note that for most parents, involvement at individual, community and system/policy levels occurs sequentially. Few parents will have either the time or inclination to serve on a policy-setting board while their family's immediate needs are not being met.

THE PROCESS

While presented as developmental, the process is not linear: a family may not enter at the first phase, smoothly move through the others and then exit. Rather, over time the family will experience many "crises" and cycle through the process again and again. With help to stabilize each new crisis, and appropriate support, information and skills, parents may increase their ability to take action to meet their child's needs. Over time, their effectiveness--both in meeting their child's needs and in changing the system--may be enhanced.

For example, a child's expulsion from school due to behavioral problems may precipitate a family crisis. With the help and support of a parent-to-parent volunteer the crisis may be stabilized. In addition, the parent may find that the law prohibits the school from expelling a child because of his or her handicap and requires the school to develop an appropriate educational program. Support and information alone, however, may not equip the parent to overcome the school's resistance to the development of an appropriate program. The parent may need the assistance of a parent advocate or negotiation, problem solving or assertiveness skills in order to work successfully with the school.

Although the school situation may stabilize, life with a child with emotional disturbances is seldom stable for long. As new crises develop--either in another setting or as the child matures and new issues evolve--the parents will likely cycle through the process again. The family will again need crisis stabilization, additional information, skills, support and task-oriented activities. While the parent may not be able to prevent the next crisis (many are normal developmental issues exacerbated by the emotional handicap), the knowledge and experience previously acquired will make it easier. Being able to work through a crisis in two hours that a year ago would have taken a week to stabilize is significant progress.

With experience, some parents become extremely knowledgeable, acquire many skills and develop a large support network. Often, these are the people who have the time and energy as well as the commitment to work for change at the system and policy levels.

APPLICATION OF THE FRAMEWORK

Once the realities families face and the process they often undergo are understood, problems can be more clearly articulated and efforts to address the issues can become more focused. This framework can serve as a guide for the development of supportive responses for specific families, as well as for the design of a community network of supportive services.

Implications for Family Support. The needs of a family with a child who has serious emotional problems reflect the stage they are in at that particular point in time.

The particular constellation of supportive services that each family receives will reflect, of course, both their preferences and the available resources. Thus, one family's need for respite care may be filled by a competent neighbor, another family may arrange an exchange of services with other families, while a third may purchase temporary respite service from a residential program.

This developmental framework also has specific implications for the organization and conduct of family support groups. For example, in a group of parents on any given night, one parent may be in active crisis, another may need information, another may want to practice negotiating skills, while a fourth wants to ventilate and get validation. Finally, two others want to change the law and increase funding. If this group of parents is brought together without acknowledging their differing needs and the developmental process, it is likely that either no member gets his or her needs met or there is a gravitation toward a single issue (e.g., legislative action) and only those interested in that task remain involved. In either situation, parents are not supported.

By stratifying the group according to their needs, yet integrating them into a flexible network, families are able to identify their needs and choose how to best meet them--moving around within the network as their needs change. For example, the resource network

could sponsor weekly support groups, schedule information seminars and offer classes for skill development. Parents who want to develop a new respite resource or change state law could meet and develop an action plan.

Implications for Community Systems. If comprehensive services to children with serious emotional disturbances and their families are to be developed, coordinated and delivered in a collaborative environment, service providers must perceive their work as one part of a larger integrated effort to address the specific needs of a child and his or her family.

A community network can be developed which recognizes the developmental process, focuses on immediate family needs, and acts as a coordinating mechanism for accessing and delivering services (see figure 1). For example, the mental health agency may administer in-home *crisis* services, offer an *informational* seminar on behavior problems, conduct a behavior management *skills* class, and sponsor a *support* group for divorced parents--all accessed through the network. In addition, the mental health agency, parents and the schools may jointly undertake the task of developing a collaborative day treatment program. Typically, services are offered to children and their families on the basis of what exists. When services are organized in response to specific needs, children and their families are more likely to receive appropriate and effective services.

A community family resource network provides the capacity within the community for families to obtain direct services, access community activities and resources, and identify and address individual and collective needs. Similarly, the network provides the capacity within the professional community to make better linkages with families, facilitate coordination with other services to better meet families' comprehensive needs, and identify gaps and develop creative collaborative efforts to address them.

Perhaps most importantly, a community network provides a neutral ground where both families and professionals can meet, better understand each other's needs and limitations, work together to develop new services and learn from one another.

Dennis Olson is a parent and a Mental Health Program Administrator, Washington Child and Adolescent Service System Program.

A Statement in Support of Families and Their Children

The Center on Human Policy recommends that the following principles guide public policy toward families whose children have developmental disabilities. We reprint them because of their applicability to families whose children have emotional disabilities:

All children, regardless of disability, belong with families and need enduring relationships with adults.

Families should receive the supports necessary to maintain their children at home. Family support services must be based on the principle "whatever it takes."

Family supports should build on existing social networks and natural sources of support.

Family supports should maximize the family's control over the services and supports they receive.

Family supports should support the entire family.

Family support services should encourage the integration of children with disabilities into the community.

When children cannot remain with their families for whatever reason, out-of-home placement should be viewed initially as a temporary arrangement and efforts should be directed toward reuniting the family.

When families cannot be reunited and when active parental involvement is absent, adoption should be aggressively pursued.

While a preferred alternative to any group setting or out-of-home placement, foster care should only be pursued when children cannot live with their families or with adoptive families.

A statement in support of families and their children. (1987, September) Families for All Children, The Center on Human Policy, Syracuse University, p. 2.

Respite Care Models

Respite care is the provision of temporary care to persons with disabilities with the primary purpose of providing relief to caregivers. Respite breaks offer caregivers an opportunity to revitalize their energies, enhance their ability to perform caregiving tasks and avoid burnout. The use of respite services enables individual family members to have time to themselves as well as socialize and participate in community activities, go to medical and dental appointments, pursue their own interests and personal growth, experience reduced levels of stress within the family, and reduce the dependence of the person with a disability--especially an older child--on the family. There are a wide range of in-home and out-of-home respite services available.

In-home models of respite care include:

Homemaker Services - Provided in the family home by a trained and licensed employee of a home care agency. Typically available twenty-four hours a day in flexible shifts on a planned or emergency basis;

Sitter/Companion Services - A single care provider, trained to work with specific disabilities, provides services on a planned and as-needed basis. A single care provider offers continuity in the relationship between the provider-family-child and the opportunity for the provider to work on specific behavioral goals; and

Parent Trainer Services - Relatives, friends or neighbors are recruited, trained and paid to provide sitter/companion services.

Out-of-home models of respite care include:

Care in the Provider's Home - May involve care exchanged among parents of children with disabilities; parents' purchasing care in the providing family's home, or volunteers providing respite services in their homes;

Foster Care or Licensed Family Care - Typically involves use of trained providers, yet maintains aspects of caregiving in a normalized home environment;

Group Day Care - Scheduled or "drop-in" care is offered by trained staff at sites often housed in churches, schools or community centers;

Residential Respite Care - Twenty-four hour a day care is provided by staff trained to work with a small number of clients with a particular disability for a weekend, a week, or even as long as thirty days;

Residential Treatment Respite Services - Occasionally, treatment facilities, state institutions and nursing homes reserve a few beds for respite services. Well trained staff and readily available back-up services make them suitable for children with severe behavioral or medical problems, and they are generally accessible when emergencies arise;

Crisis Nurseries and Emergency Respite Care Facilities - Designed as a supportive service to families who are temporarily unable to care for their children, or whose children are at risk of abuse or neglect. Here the program focus is on family needs that are not directly related to a child's handicapping condition; and

Generic Community Services as Respite Care - Community services available to the general population (such as camps, school and after school activities, organized sports, and crafts classes) have a side effect of providing parents with some relief from caregiving tasks.

These respite care models are more fully described in *Respite Care: A Monograph*, a new publication of the Portland Research and Training Center. More than forty respite care programs around the country reviewed by author Terry Butler are included in the information base on which this monograph was developed.

Thirty-six articles addressing a range of respite care issues are summarized in *Respite Care: An Annotated Bibliography*, another new Center publication. The respite issues discussed include: the rationale for respite services, family needs, program development, respite provider training, funding and program evaluation. See page 15 for ordering information for both publications.

National Parents' Planning Meeting

Ten parents whose children suffer from serious emotional problems met in Washington, D.C. in January, 1988. The parent participants brought a wealth of expertise and experience with parent organizing efforts in a variety of settings. The meeting was organized around these major purposes: to address issues of organizing family support systems at the local, state and national levels; identify Federal resources needed to promote the development of family support systems; and develop an agenda for action.

The meeting was sponsored by the Families as Allies Project of the Portland Research and Training Center, and was hosted by Barbara Friesen, Families as Allies Project, and Glenda Fine, Parents Involved Network, Mental Health Association of Southeastern Pennsylvania. Naomi Karp, National Institute on Disability and Rehabilitation Research, and Dr. Ira Lourie, Child and Family Support Branch, National Institute of Mental Health also attended.

Participants developed a statement of beliefs and a set of principles and goals, examined the resources needed by parent organizations to achieve their goals, developed a set of recommendations, and identified "next steps." Members of the working group presented their recommendations to Madeleine Will, Assistant Secretary, Office of Special Education and Rehabilitative Services, U.S. Department of Education (USDE). The recommendations outline steps that the USDE and other Federal agencies can take to increase the attention given to the problems and needs of children with emotional disabilities and their families. The discussion of recommendations was also attended by Patty Smith, Deputy Assistant Secretary, Office of Special Education and Rehabilitation Services, and other USDE administrators.

A copy of the full report of the meeting is available through our Resource Service. The statement of principles is reprinted here:

1. Family support systems should be rooted in a philosophy or mission--a statement of how families should be regarded and involved, and how services should be developed, implemented and evaluated.
2. Family support should be acknowledged as a necessary, legitimate part of the system of care for children who have serious emotional problems and their families.
3. Much support and assistance to families is currently provided voluntarily by parents. These efforts must be supplemented with funding for the development and maintenance of parent support efforts.
4. Family support groups/efforts must be flexible, recognizing that families are different from one another, and that the needs of a given family are likely to change over time.
5. Family support services should be offered in a way that is sensitive to the cultural backgrounds of families.

Dreams

All parents have dreams for their children. They dream of happy faces, bright eyes on the world around them, and laughter that fills the air. They dream of recitals, sport events, school grades and the first school dance. Parents dream of the love they will share with their children.

When a child or adolescent is stricken with mental illness, all too often, these dreams are shattered. The process of building new dreams for the emotionally disabled child or adolescent is replaced by pain and conflict. Feelings of aloneness and isolation from family and friends grow. Anger and guilt often build because parents wrongfully blame themselves for their child's emotional disability.

Parents, confronted by an underdeveloped and complicated children's mental health system, struggle to find appropriate and consistent professional care. School programs become equally as frustrating to deal with, especially when everything else seems so overwhelming. Many parents are trying to deal with this tremendous struggle without support, without caring and most importantly, without understanding what happened to their dream. It is time to care.

Adapted, with permission, from the May-June 1987 Parent Support Network newsletter of the Mental Health Association of Rhode Island's Adolescent Mental Health Support Project and from the inaugural November 1987 issue of the Erie County, Pennsylvania parent support group's Family to Family newsletter.

Why Not?

I vividly remember the dilemma of little Jessica McClure lying helplessly 20 feet below the surface of the earth in Midland, Texas. Aside from the sorrow we all felt for the little one and her family, an overwhelming sense of pride and optimism emerged as most of America viewed the long and tedious rescue effort.

As I watched Jessica's ordeal, the entire experience brought with it a sense of vague familiarity. This little girl who fell in a deep dark hole in the ground, who was not only lonely and helpless, but completely out of touch with her environment, reminded me of what severely emotionally disturbed children must experience.

The SED children and adolescents with emotional disabilities that I know often live in a world of despair--a deep dark hole. They are lonely, out of touch and crying for help. What made the difference for little Jessica is that her cries were heard. An entire community pulled together a coordinated effort that resulted in success. If they could do it, why not us?

If we pull together the existing resources in each community and mobilize these resources similar to the Midland, Texas experience we, too, could elevate the quality of life for severely emotionally disturbed children. The question is not "HOW?" The question is "WHY NOT?"

Susan C. Ignelzi, Ph.D., Ohio Child and Adolescent Service System Program Project Director.

Parents' Perspective

My Winter '88 issue of *Focal Point* came in the mail today. I was really excited by the amount of information. I can't tell you how heartening it is to hear that there are so many other parent groups across the country dealing with the same issues, and in many cases much more advanced in their level of organization and advocacy. However, these little excerpts are not enough. I want to know more!

I am the mother of a seven year old son who has been in the seriously emotionally disturbed program in our district for more than two years. When he was first placed there was no organized parent group, although the San Diego Unified School District does have parent facilitators, who are parents employed to advocate for other parents. I got together with the parent facilitator and a couple of teachers of seriously emotionally disturbed (SED) children, and we started the Parent-Teacher Association for Seriously Emotionally Disturbed Children (PTA for SED). We started a successful parent support group, worked on local issues, and held a few social events. I'm on the local advisory committee for special education, and am taking a course in parent professional collaboration at the local university.

My problem is I feel extremely isolated as the parent of a child with an emotional or behavioral disability. I feel sure that my parent group is reinventing the wheel.

Who are the active people in California? Have you heard from other SED parent groups in California? Where are they? What professional organizations should I join to get in touch with developments in the field? What is CASSP? What conferences should I try to go to if I want to find other parents working on their own local issues around emotionally disturbed children? What journals or newsletters should I subscribe to?

I know these are a lot of questions, but your newsletter was really like a light in the tunnel to me.

Marian Thacher, San Diego, California.

Editor's Note: Families as Allies Training Coordinator Richard Vosler-Hunter responded to Ms. Thacher's inquiries by letter. Parents are invited to submit articles, not to exceed 250 words, for the *Parents' Perspective* column.

Why Parents Should Become Allies with Professionals

As parents of emotionally disturbed children we are used to dealing with mental health professionals. Our lives are often littered with professionals. We make a trail from one professional to another--social workers, psychologists, psychiatrists, ministers, nurses, special education teachers.

As we pass from hand to hand, always hoping to find help and solutions to our children's problems, we are often viewed as the client or patient. At best the relationship between parent and professional is often paternalistic; at worst, it can be condemning.

The two most important elements in helping our children are the professionals and we, the parents. Our children are best served when parents and professionals work together as allies, recognizing the unique contribution each can make to the welfare of the child.

It is a tremendous relief when we can communicate as adult equals with professionals who understand and care about our peculiar problems as parents of emotionally disturbed children. This type of communication improves care opportunities for our children.

An additional and very important aspect of an alliance between parents and professionals is the combined effect our efforts can have on forcing changes in the system. Working together we can increase services, bring about innovations, and encourage the legislature to increase budgets for services.

Parents allied with professionals can bring about benefits for our children that each of us working separately cannot possibly obtain.

Catherine Staib, Lexington, Kentucky.

Why Involve Parents?

In recent years it has become almost a cliche in children's mental health that one must "involve the whole family" to be effective. It is ironic that much of family systems theory, by reinforcing the notion that the family's interactions are the cause of the child's problems, has subtly reinforced the notion that parents are the actual cause of the child's problems. Consequently, even many of those professionals who embrace a family-based treatment philosophy have a tendency to view parents as clients only, rather than partners or allies.

For many professionals the parent-as-client role does not denote parent-professional equality and partnership but rather a helper-helpee relationship that can appear patronizing to the parent.

At the root of our need to form partnerships with parents is a belief in the inherent value and uniqueness of every child and family. If we accept the idea that the needs of children are multiple, varied and change with time, parents are the obvious source of information to keep us informed of these needs. Parents usually know the particular strengths, resources, needs, and problems of their children and will, *if given the opportunity*, ensure that services are sensitive to these characteristics.

Another reason for parental involvement is that as consumers parents have a right to be involved in the decision-making process related to their families. Because children with emotional problems frequently require services from more than one service system, parents are often the most knowledgeable and effective case managers for their children.

Because of their continuing and intensive contact with the child, the family unit and especially the parents are often the most powerful therapeutic resources in the on-going treatment process. Informed and involved parents may serve as an on-going support for the child which may not only ameliorate current problems but also prevent future emotional disturbances. Consequently, interventions that involve parents as partners are both clinically effective and cost efficient.

Professionals often complain that parents do not accept their share of the responsibility for caring for their children with emotional problems. However, when they are invited by professionals to assume an *active* and *equal* role in

planning, implementing, and evaluating these services, they will naturally increase their acceptance of this responsibility.

Finally, and perhaps most importantly to professionals, parents must be included as active partners with their professional counterparts in order to inform policy-makers of the most important service needs of their children and families. The lack of parent-professional advocacy coalitions in the children's mental health field has contributed to the current lack of effective community-based services for children with emotional problems. As consumers, taxpayers, and voters, informed and involved parents are our best and perhaps last hope for a system of services for our children and families.

Bill Scott, MSW, Kentucky Child and Adolescent Service System Program Project Director.

"Why Involve Parents?" and "Why Parents Should Become Allies With Professionals" are reprinted with permission from the Kentucky Families as Allies Newsletter, (Winter 1987-88), (1) (1), p.1,4.

Working Together—Groundbreaking in Alaska

Parents, service providers, educators, advocates and legislators recently met in a weekend retreat to work together on behalf of Alaska's mentally ill and seriously emotionally handicapped children. On March 18-20, 1988, about sixty participants from around the state met to prepare recommendations to the State Mental Health Board about how the needs of Alaska's children with serious mental or emotional disorders should be addressed. The meeting also provided an opportunity for parents to meet and begin organizing to meet their support, education and advocacy agendas.

The meeting was co-sponsored by the Alaska Child and Adolescent Service System Program (CASSP) and the Alaska Alliance for the Mentally Ill (AMI). John VanDenBerg, CASSP Coordinator, and Sharon Lobaugh, of Alaska AMI, welcomed participants and presented the agenda for the meeting. James Mason and Barbara Friesen from the Portland Research and Training Center served as speakers and resource persons. The work of participants was organized around four themes: (1) development of parent support/advocacy groups; (2) development of advocacy and systems change efforts involving parents, professionals and other interested citizens; (3) development of a blueprint for a system of care for Alaska's children and their families; and (4) coordination of these efforts with those of other task forces, commissions, and groups working to address the needs of Alaska's youth.

Participants created not only a set of recommendations for the Alaska Mental Health Board, but began to build structures for a parent network and an organization for advocacy and systems change. The group produced many innovative ideas, demonstrating the ability to look at old problems in new ways, in particular from the perspective of the child and family.

A highlight of the meeting was a discussion of the Alaska Youth Initiative (AYI) by parents and staff involved in the program. AYI is a demonstration project created by the Alaska Department of Education and the Alaska Department of Health and Social Services to develop individualized services for Alaska's most troubled youth; those who have traditionally been served outside of Alaska. An AYI intervention involves an interagency process of individualized case planning and implementation using a "dollars follow the child" funding and "wrap around services" framework. This approach in-

Jim Orvik and Jody Engelman, participants in a weekend retreat to develop recommendations for Alaska's State Mental Health Board on the needs of children with mental or emotional disorders. (Photos by Barbara Friesen.)